PATIENT & CAREGIVER EDUCATION

# Talking With Your Child About Inherited Cancer Risk

This information can help you get ready to talk with your child or children about their inherited cancer risk. It also has tips for managing challenges you may face and a list of helpful resources.

## Introduction

If you or your family member is diagnosed with cancer, it can bring up many feelings. Learning a gene mutation may have caused the cancer can add reactions and emotions to an already hard experience.

It’s important to take time to process your own feelings and questions before talking with your child. If talking about a gene mutation in your family feels overwhelming or you’re struggling to manage your own distress, we can help. You can get support through counseling or by talking about your concerns and questions with a genetic counselor. Visit www.msk.org/genetics to learn more about MSK’s Clinical Genetics Service and genetic counselors.

### Words and phrases to know

A **gene mutation** is a change in your genes. Gene mutations are common. Most do not affect your health, but some can raise your risk of getting certain illnesses, such as cancer.

An **inherited gene mutation** is a gene mutation that’s passed from parent to child before the child is born. An inherited mutation is also called a hereditary (heh-REH-dih-tayr-ee) mutation.

**Inherited cancer risk** is cancer risk caused by an inherited gene mutation. Inherited cancer risk is sometimes called hereditary cancer risk.

You can also watch our videos *Understanding Genes and Hereditary Cancer Risk* (www.mskcc.org/pe/genes-hereditary-cancer) and *Understanding Genetic Testing for a*

*Gene Mutation Found in Your Family* (www.mskcc.org/pe/genetic-testing-family-mutation) to learn more.

# Talking about inherited cancer risk

If there’s a gene mutation in your family that your child may have inherited, you may wonder how to talk with them about it. What to say can depend on how the mutation affects your child’s cancer risk.

- Some gene mutations raise cancer risk even for children. For these mutations, testing children is recommended. Cancer screening starts if their test result is positive. A positive result means the test showed they have the mutation.
- Some gene mutations do not raise cancer risk until adulthood. With these mutations, testing and screening do not start until a certain age because the risks are different.

This resource uses examples from both situations.

There are lots of things to think about before telling your child about a mutation in your family. This resource can help you plan how and when to talk with your child. It can also help you think about what to talk about based on their age and maturity. Being open with your child will help build trust over time while letting them feel valued and safe.

**Every child is different. This resource is meant to be a guide. It may not apply to every situation or child.**

## Why talk to your child about inherited cancer risk?

Many people worry about burdening their child or causing unneeded worry. But there are known benefits of sharing this information with children. Being open and honest with your child can help them feel less afraid and anxious, and build trust. If your child is older, talking about inherited cancer risk can help them feel in control of their health. It can also help them make plans for the future.

If you don’t think your child is ready to know everything, sharing even some information is helpful. This is even more true for younger children. Children need to know enough to be prepared. And knowing what’s happening can help them avoid imagining things are scarier than they truly are.

Your child can also get information on their own from their friends and the internet. This information is not always correct. You play a key role in helping prevent misunderstandings. You can offer a space where your child feels free to ask questions and get accurate information, now and in the future.

# Getting ready to talk to your child

It’s OK to feel nervous. It’s important to remember that there’s no one right way to have this type of discussion. Every family and family member is different.

## Ask for help getting ready

Making a plan with an MSK provider with special training in cancer risk and child development can be helpful. Psychologists, social workers, and child life specialists are examples of these providers. Genetic counselors can also help you plan for talking with family members, including children.

It may be helpful to make a script or practice the conversation ahead of time. Try practicing with a genetic counselor or with a partner or other family member who knows you and your child.

## Think about what your child knows

Thinking about what your child already knows will help you plan where to start the conversation. For example:

- Do they know about cancer in your family?
- Did they know their relative was having genetic testing?
- Have they started learning about genes or genetics in school?

Starting with information your child already knows can help the conversation feel less unfamiliar or forced. If you aren’t sure what they know, try starting the conversation by asking them.

## Plan to have more than one conversation

You do not need to share everything during one conversation. Sharing information over several conversations can encourage an open and ongoing discussion. And sharing small bits of information at a time may help your child take time to process without feeling overwhelmed.

Think about your child’s age, maturity, and personality when you’re deciding how much to share and how quickly to share it.

### Be flexible and honest

Follow your child's lead. Answer their questions directly and honestly. It's OK to tell them when you don't know an answer. For example, you could say, "That's a great question, and I'm not sure about the answer. Let's ask our doctors who are experts in this to help us both understand."

### Check in with your child after talking

Think about asking your child what their "take-aways" are after you speak. This can be a main point or key message they learned. Their priorities, concerns, or questions are probably different from yours as a parent or caregiver. Their answers may surprise you!

## Challenges you may face

### Starting the discussion

The first challenge you may face is just starting the discussion. It's easy to feel like no time is the right time. You may have hoped the conversation would happen naturally, but it has not.

If you find yourself putting off talking with your child, think about setting aside a dedicated time to have the first conversation. Even putting it on your calendar might help. You might also find it helpful to rehearse your first line or two so it's easier to get started.

It's OK if your first conversation with your child doesn't go exactly as planned. Remember, ongoing communication often works better than a single conversation. As your child processes the information, their questions and feelings may change.

### Answering questions

Another challenge you may face is your child having questions you don't know how to answer. Kids are smart and creative with unique ways of seeing things. They may ask questions you don't expect. It's OK to be honest that you don't know the answer. Write these questions down and ask your genetic counselor or doctor. You might learn more from figuring out the answers together.

Your child might also ask questions no one knows the answer to, like "Will you get cancer again?" It's OK to be honest about what isn't known. Reassure them that you're taking steps to protect yourself so you can be there for them.

For children of all ages, make sure you're answering the question they're actually asking rather than the question you think they're asking. For example, sometimes a question like "Will we be OK?" may have multiple meanings. It's important to understand what your child is really asking. It's OK to not answer right away and instead ask for clarification. For example, you could ask "What made you think about that?" or "What exactly do you mean about being OK?"

### After the first conversation

You may walk away from the first conversation thinking that your child didn't "get it." Maybe they were quiet and didn't ask questions or acted bored or like they weren't interested. For kids of all ages, this can be a normal reaction to information they don't know how to respond to.

It's OK if your child doesn't say much during the first conversation. They will likely process what you've said in their own time. They may or may not bring up the topic again later. It may be helpful to repeat that you're available and welcome them to talk more whenever they want to and feel ready.

## Helpful resources

### For elementary school children

- *Let My Colors Out* by Courtney Filigenzi and Shennen Bersani, ages 2 to 4
- *It's OK To Be Different* by Sharon Purtill and Sujata Saha, ages 2 to 5
- *Mom and the Polka-Dot Boo-Boo: A Gentle Story Explaining Breast Cancer to a Young Child* by Eileen Sutherland and Maggie Sutherland, ages 2 to 5
- *Cancer Hates Kisses* by Jessica Reid Sliwerski, ages 3 to 5
- *Butterfly Kisses and Wishes on Wings* by Ellen McVicker (also available in Spanish), ages 4 to 8
- *Cancer! Explaining Cancer to Kids* by Prodigy Wizard Books, ages 4 to 8
- *My Dad Has Cancer* by Lauren Faye Uribe, ages 4 to 8
- *Grow: Secrets of our DNA* by Nicola Davies and Emily Sutton, ages 5 to 9
- *Enjoy Your Cells* by Fran Balkwill and Mic Rolf, ages 7 to 10
- *Gene Machines* by Fran Balkwill and Mic Rolf, ages 7 to 10
- *Have a Nice DNA* by Fran Balkwill and Mic Rolf, ages 7 to 10

## For adolescents

- *You Can't Wear These Genes* by Shirley Duke
- *Navigating Emotions: A Guide For Teenagers with Rare Diseases* (online brochure)
  globalgenes.org/wp-content/uploads/2019/01/GG_toolkit_navigating-emotions_web-hyperlinked-5-1.pdf

## For young adults

- Bright Pink
  www.brightpink.org
  This is a support organization for young adults with a *BRCA* mutation or who have a family member with a *BRCA* mutation.
- FORCE (Facing Our Risk of Cancer Empowered)
  www.facingourrisk.org
  This is a support organization for individuals and families facing hereditary cancer. They offer information, support resources, and ways to connect with others affected by hereditary cancer.

## For parents

- *How Do I Tell My Children About My Cancer Gene Mutation?* (online brochure)
  https://sharsheret.org/wp-content/uploads/2022/03/Genetics-Brochurre-March2022.pdf
- *Talking About BRCA in Your Family Tree* (online brochure)
  www.facingourrisk.org/uploads/brochures/booklet-talking-about-brca-family.pdf

MSK's Talking with Children about Cancer program offers support and resources for people who have been diagnosed with cancer and are caring for children or teens. Learn more at the webpages below.

- Talking with Children about Cancer
  www.msk.org/experience/patient-support/counseling/talking-with-children
- Talking with Children about Cancer: Support for Parents
  www.msk.org/experience/patient-support/counseling/talking-with-children/support-parents
- 10 Tips for Talking with Your Child about Cancer
  www.msk.org/news/ten-tips-talking-your-child-about

## More resources

- *Mom’s Genes: Empowering children to learn about their family’s health history* by Shannon Pulaski
- *Robot Music: A Story for Kids with Li-Fraumeni Syndrome and Other Cancer Predispositions* by Amy Peasgood and Ruby Peasgood
- *LFS & Living My Best*, ages 8 to 13
  www.msk.org/pe/lfs-living
- *BWS and You: An Educational Coloring Book*
  https://media.chop.edu/data/files/pdfs/bws-coloring-book.pdf

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you’re not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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November 21, 2023
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